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Perceived need for information and treatment decision-making in patients with hematological malignancies

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SUMMARY

This thesis aimed to investigate the perceived need for information, the satisfaction with information provided, and the shared decision-making (SDM) preference from the perspective of both patients with a hematological malignancy (HM) and their informal caregivers as well as from the perspective of their healthcare professionals (HCPs). First a literature review was conducted on the current knowledge on the perceived need for information among HM-patients. Then, a questionnaire was composed to assess the perceived need for information and satisfaction with information provided and was used in a cross-sectional study to obtain detailed insight into the perceived need for information among HM-patients, their satisfaction with the information provided, and their preference for SDM. Also, possible sociodemographic and clinical moderating factors, health related quality of life (HRQOL), and cognitive coping style were explored. Subsequently, we investigated the way HCPs may tailor information to individual HM-patients. Furthermore, the information needs- and satisfaction, and SDM preference among newly diagnosed patients and their informal caregivers were studied, in relation with possible sociodemographic and clinical moderating factors, HRQOL and cognitive coping style. Finally, we shortened the HM-specific information needs questionnaire and investigated further the psychometric characteristics of the questionnaire.

Chapter 2 described a literature review on the, at that time, current knowledge on the perceived need for information of HM-patients, in which fourteen studies were included. Results showed that patients need basic information on the disease (diagnosis and diagnostics), treatment (various treatment options, side-effects and duration), prognosis (curability and prolonging life) and all other topics (recovery, self-care and psychosocial functioning). Need for detailed information varied between studies. Patients expressed a higher need for medical than psychosocial information. Patients preferred to receive information from their doctors the most, followed by nurses. Most studies described patients' satisfaction with the information provided, ranging from 52 to 67% satisfied patients. However, most of the included studies used study-specific questionnaires, with a limited number of patients, mostly HM survivors, and multivariable analyses were rarely performed, which underlines the need for more studies investigating the need for information among HM-patients as well as their informal caregivers.

Chapter 3 focused on the perceived need for information and SDM preference of 458 HM-patients ranging from diagnosis to up to more than five years after diagnosis.

We compiled a questionnaire with existing validated questionnaires. The perceived need for information was moderate to high (40–70%). Multivariable regression analyses showed that a higher need for information was related to younger age, worse HRQOL, being member of a patient association, and moderate comorbidity. The need for disease- and treatment-related information was higher than the need for psychosocial information. A higher need for psychosocial information was related to a lower educational level. The information provision could be improved according to 41% of the patients. Higher satisfaction with provided information was associated with better HRQOL. Most patients (82%) reported that they wanted to be fully informed about their illness and actively involved in treatment decision-making.

A HM is a serious, life-altering disease, and may be characterized as an uncontrollable and unpredictable stress situation. In dealing with potentially threatening information, individuals generally utilize two main cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and seeking distraction). The aim of **Chapter 4** was to obtain insight into the association between cognitive coping style and 1) need for information, 2) satisfaction with information, 3) involvement in decision-making, and 4) HRQOL. In a cross-sectional study, coping style was assessed among adult patients diagnosed with a hematological malignancy, using an adapted version of the Threatening Medical Situations Inventory. Information need, information satisfaction, decision-making preference and HRQOL were measured with validated questionnaires. In total, 458 patients returned the questionnaire (66%). A monitoring cognitive coping style (MCCS) was positively related to need for both general and specific information. Blunting was positively and HRQOL was negatively related to need for information. Monitoring was positively related to involvement in decision-making and negatively to information satisfaction. Using multivariable analysis, this relation between monitoring and information satisfaction disappeared and for blunting we found a negatively significant relation. HRQOL was not related to coping style. It was concluded that coping style is related to a need for information, information satisfaction, and involvement in treatment decision-making. Therefore, it is important for HCPs to be aware of individual differences in cognitive coping style.

The aim of the study described in **Chapter 5** was to investigate the SDM preference and the satisfaction with and need for information among newly diagnosed HM-patients and their informal caregivers, in relation to sociodemographic and clinical factors, cognitive coping style, and HRQOL. Newly diagnosed patients and their caregivers were asked to complete the Hematology Information Needs Questionnaire, the Information Satisfaction

Questionnaire and the Threatening Medical Situations Inventory. Medical records were consulted to retrieve sociodemographic and clinical factors and comorbidity by means of the ACE-27. Questionnaires were completed by 138 patients and 95 caregivers. SDM was preferred by the majority of patients (75%) and caregivers (88%), especially patients treated with curative intent), and patients and caregivers with a higher M CCS. Among patients, total need for information was related to M CCS, and need for specific information was related to M CCS and several clinical factors. Importantly, dissatisfaction with the information they received was reported by a third of the patients and caregivers, especially patients who wanted SDM, and patients with a higher M CCS. It was concluded that the majority of HM-patients want to be involved in SDM but the received information is not sufficient. Patient-tailored information is urgently needed, in order to improve SDM.

In cancer care, it is known that patients' information needs do not always correspond with the information received from HCPs. This may influence patients' involvement in treatment decision-making, satisfaction with care, and health-related quality of life. The aim of this study described in **Chapter 6** was to explore the perspectives of HCPs on the need for information of newly diagnosed patients with hematological malignancies, and whether the estimated need was associated with HCPs' own cognitive coping style, sociodemographic and work characteristics. Ninety-six hematologists and 27 specialist nurses completed the adapted version of the Hematology Information Needs Questionnaire regarding fictive newly diagnosed patients. HCPs' age, gender, years of work experience, hospital affiliation, and cognitive coping style were assessed. HCPs ranked information concerning disease, treatment, side-effects, medical tests and prognosis higher than psychosocial and selfcare information. Need for information on selfcare was estimated higher in female HCPs and in HCPs with a higher monitoring coping style. Need for information on medical tests and prognosis was estimated higher in HCPs with a higher monitoring cognitive coping style. It was concluded that HCPs do only slightly tailor information to individual patients. HCPs should be aware that their own cognitive coping style affect their estimation of their patients' need for information.

As a validated HM-specific information needs questionnaire with specific items associated with HM and their treatment were not available, we developed and validated the Hematology Information Need Questionnaire (HINQ-62), described in **Chapter 7**. The psychometric characteristics (content validity, internal consistency, and subscale structure) HINQ-62 were investigated. Baseline data were used from a prospective study on the need for information among 336 newly diagnosed HM-patients. In cohort

1 (design phase), data from the first 135 patients were used and in cohort 2 (validation phase), data from the remaining 201 HM-patients were used. None of the 62 HINQ-items were irrelevant. Exploratory FA identified five subscales: “disease, symptoms, treatment and side-effects”, “etiology, sleep and physical changes”, “selfcare”, “medical tests and prognosis”, and “psychosocial”. Root Mean Square Error of Approximation (RMSEA) among patients was 0.037 in cohort 1 and 0.045 in cohort 2. The comparative fit index (CFI)/Tucker-Lewis index -non-normed fit index among patients was 0.984/0.983 and 0.948/0.946, in cohort 1 and 2 respectively. The internal consistency of the subscales was good, with Cronbach’s α 0.82–0.99. It was concluded that the HINQ is a valid questionnaire for assessing the need for information among Dutch HM-patients at diagnosis.

In **Chapter 8** is the research in this thesis summarized, that provides a better understanding of HM-patients and caregivers need for information and SDM, and their satisfaction with the information provided, both from the perspective of HM-patients and informal caregivers and from the perspective of HCPs. The need for information and SDM was high. Importantly, we found that more than thirty percent of the patients were dissatisfied with the information they received. The most important factor associated with this dissatisfaction was a monitoring cognitive coping style. Furthermore, it appeared that the satisfaction with information was not merely related to the need for information. This finding indicates that the amount of information should not just be increased, but much more personalized. However, HCPs do not seem to tailor the information to the individual (fictive) patient, indicating that HCPs should be much more aware of the diverse needs of their patients. More research is needed on how to tailor information to HM-patients and their caregivers that may change over time. Possible ways to improve personalized information that might be explored are a tool that can be used in clinical practice to predict patients’ cognitive coping style and associated need for information, and an online clinical decision support application to provide tailored information.